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ABSTRACT

Written for parents of children with cancer and leukemia, the booklet considers the psychosocial aspect of the conditions as well as the effects on the family and child. Part I reviews emotions experienced by parents at the time of the initial diagnosis and through the course of the illness. Marriage strain, support sources, and relatives are among the factors considered. Part II discusses what the healthy child knows about death and what the seriously ill child knows about his illness. Also considered are hospitalization, home life, and ways of communicating with the child. (CL)

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EMOTIONAL ASPECTS OF CHILDHOOD CANCER AND LEUKEMIA: A HANDBOOK FOR PARENTS

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INTRODUCTION

This booklet is written for parents who are trying to lead a normal life in spite of a difficult situation. It is for parents of children who have cancer, who seek to face the illness with all of its ramifications and deal with it in a psychologically healthy manner.

The diagnosis that your child has a life-threatening illness must have come as a staggering blow. This illness has been cast upon you without warning and for no comprehensible reason. Yet your ability to cope as a parent is essential, since your ill child may have years of valuable life ahead. A child with a serious illness continues to achieve and develop. He or she is entitled to as healthy an environment as possible.

Equally important is retaining a healthy relationship among you, your spouse, and your other children. This is not always easy because of the added stress of your child's illness.

While each family and each child within a family is unique and while each family's past experiences, individual personalities, economic and social standing, political and religious orientations differ, parents of seriously ill children share many common experiences and feelings. We have reviewed and will share with you the writings and research of psychologists, psychiatrists, social workers, physicians and nurses, both on the psychosocial aspects of childhood cancer and on the effects of the illness on the emotional life of the family and child. Many parents of children with cancer graciously shared their experiences with us.

For convenience, this booklet is divided into two sections.

Part I: You, the Parent

In Part I, we will review some of the emotions experienced by parents whose children have cancer. Feelings of confusion, denial, fear, anger, guilt, grief, hope and belief in life are not uncommon. We will also discuss some of the new demands placed on you, the parent, as well as sources of support and assistance.

Part II: You and Your Children

Since most parents are concerned about what their child knows about his illness, we will discuss what the healthy child knows about death and what the seriously ill child knows about his illness. We will also talk about hospitalization, home life, and ways of communicating

with the child.

Brothers and sisters of a child with cancer have needs, too. These are sometimes forgotten because of the immediate and pressing problems of the sick child and the emotional upset of the parents. The parent who listens to the other children in the family, who leaves openings for the well children to voice any and all concerns, establishes a pattern of honesty and openness and builds a bridge to last a lifetime.

These two sections are not mutually exclusive. Parents and children always interact and the response of one to the situation influences the responses of the others. You may find things in this book that do not apply to you and to your family. This is fine. Take what you can, think about it, and move on from there. Reading this booklet will not be painless. It is quite painful to look at and think about a child with cancer. Some might want simply to run away from it. But the parent who can take the pain and look at the realities of the illness is much better equipped to deal with the problems involved.

PART I: YOU, THE PARENT

THE INITIAL DIAGNOSIS

The shock of diagnosis produces a bewildering number of emotions. You may have experienced some or all of the feelings discussed below. You may have experienced them at different times and with different degrees of intensity than other parents, but you are not alone in this experience.

Confusion. After your doctor told you the diagnosis and perhaps even after a lengthy explanation, you heard nothing but that your child has cancer. The statement of the disease has blocked out everything else. Physicians understand this initial confusion and are usually most willing to repeat the explanation as often as necessary for you to fully understand it.

Denial. After a complete explanation, you want to believe it is a mistake. "This cannot happen to my child." "The doctor must be wrong." "I just will not believe it." Some parents become so adamant in their denial that they take the child from hospital to hospital in the hope that some doctor someplace will contradict the diagnosis. This can have negative effects on the early adjustment of the parents and the child.

It is hard to accept the fact that your child's span of life may be limited. The first few days you may continue to talk as if nothing were wrong and continue to plan for your child's future. That is all right for a short period of time. It takes time to adjust and shift gears. However, denial for a long period of time is detrimental to the future happiness of the child and the entire family. Denial practiced continually only succeeds in isolating the child and leaves him totally alone when he needs you most.

Fear. You will experience many fears: fears about the health of your other children, fears of how expenses will be handled, fears about what relatives and friends will think and say, fears about your own ability to handle the situation. Talk about these fears. Get them out in the open. The health care team includes social workers, nursing personnel, and other specialists trained to help you with all aspects of the illness: physical, emotional, and financial. Get to know each person on the team, and how they can help you.

If your relatives are helpful and supportive, consider yourself lucky.

They can be a source of strength and understanding. Unfortunately, many relatives are not helpful. They may deny the illness. They may have countless stories of spontaneous remissions. Some offer home-made remedies. Some frown if you take a few hours out alone with your spouse. If your relatives act in these ways, try not to be disappointed. Remember, it is your child and your family. You and your doctor will do the best you know how.

Professionals who work with families of children who have cancer often observe that parents develop an ability to adjust which permits them to meet the threat to their life and happiness and function very effectively. Parents who were shocked and hurt by the diagnosis come to discover strengths they never dreamed they possessed.

Anger. Don't be surprised if you feel angry—very angry. You may, like some parents, feel angry at being singled out by God or a cruel fate, or at your doctor or the entire medical profession for not finding an immediate cure for your child. Occasionally, you may even find yourself getting angry with your sick child for becoming ill. Open manifestations of such anger are hardly possible, for who could dare to be angry with the sick child? So, often such emotions are displaced onto other family members. Spouses and well children can become scapegoats for unresolved feelings.

It is all right to feel such anger, even though it is irrational. It is even fine to "blow your cool" sometimes. But it is even better if, early in your child's illness, you find some harmless outlet for your anger, rather than inflict it on spouses and children who have feelings and are hurting, too. Now more than ever the support given to and by family members is of prime significance.

Guilt. Anger may be followed in a few days by feelings of guilt. You think you must have done something horribly wrong to your fellow man and now you are paying for it. You reflect on your past and search for your mistakes.

You must accept that whatever it is that caused your child to have cancer will largely remain a mystery. Feelings of guilt can cause other serious problems.

> Mrs. S. saw her son's illness as a punishment from God for her marriage to a divorced man. She turned away from her husband, refused to sleep with him. Her husband felt that he had lost both his wife and his son.

This wife's misplaced guilt created a marriage problem just when the closeness of the marriage relationship could have been a source of great comfort and strength.

Grief. You may feel an acute sense of loss the moment the diagnosis is made. This sense of sorrow may deepen the longer you live with the truth of the diagnosis. Rare is the parent who does not feel sometime during the course of the illness a conflict between giving the child all he can here and now to make his life as complete as possible and, on the other hand, a need to prepare at least in some small way for the time when the child may no longer be here. However, too much mourning too early can make the child feel isolated and alone.

You must be sensitively aware of how early grief can affect your child. Yet, parents who do not begin to mourn until after the death of the child appear to have the most difficult adjustment after the death. This anticipation of the possible future death of the child and subsequent life without the child is a very normal process and you should not feel guilty for these kinds of feelings nor unduly upset over the conflict.

Hope. Unlike denial, hope does not interfere with healthy adjustment and is entirely compatible with an acceptance of reality. Hope is a sustaining human quality, and the important role it plays in all meaningful behavior is not to be underestimated. As one doctor has written, hope of improvement is the motivation behind every dose of medication prescribed. Hope provides strength in maintaining the will to live. To give up hope is to give way to despair and sorrow.

Belief in Life. The seeming injustice of your child's illness can threaten your basic optimism about the meaning and value of life. It is easy to become bitter and cynical. Most parents quickly realize that bitterness and cynicism have no positive value and continue to believe in life. They attempt to make the most of the child's life while fully acknowledging his possible life-threatening prognosis.

Along with grief and anger, many parents discover riches they never before appreciated: closeness and support of family and friends, availability of good medical care, continued belief in life, and small things in life for which they feel grateful. Much of their continued belief in life takes the form of counting their blessings. They assert that the emotional investment in life is worth the risk despite the loss they are facing.

NEW DEMANDS

Parents of children who have cancer find that, as they are trying to adjust to the reality of the diagnosis, they are forced to exert energy to take on new demands. Theories in physiology and psychology tell us that many untapped energies and skills lie dormant in a person until he really needs them. You will need your untapped resources as you attempt to meet the demands placed upon you by the very nature of the illness.

What are some of these demands? First, there are immediate medical decisions that must be made. If you have been referred to a large medical institution for complete diagnosis and treatment, you may have to cope with a very sick child in a new hospital and with a new physician. Secondly, you must quickly decide how to explain the nature of his illness to the child, giving adequate information to insure his cooperation with medical treatment and his emotional well-being, but without frightening him. You must answer the questions of relatives and other children. Finally, you must get in touch with your own feelings, evaluate the situation, and reevaluate your goals. These are not easy tasks.

Disagreements and Compromise. Even though you are quite capable of facing and resolving some of the issues related to childhood cancer, it is not uncommon for parents to disagree on important issues. Emotionally, parents may react differently to the initial diagnosis. If parents disagree over the implications of the illness, if they differ as to medical treatment required, or if they hold opposing views as to what to tell the child, the brothers and sisters, or the relatives, the ingredients are present for failure of the individual and the family to adjust.

Disagreements must be resolved. The process may be uncomfortable, but if the differences are not resolved, the care and emotional support of the sick child will deteriorate. Major disagreements can produce garbled and confused conversations about the illness or prevent communication about it, prohibit and interrupt individual and collective grieving within the family, and weaken family relationships when they most need to be strengthened.

When you cope successfully with the first tasks required by the illness, you lay the foundation for successful coping with future tasks. On the other hand, if, from the very beginning you and your spouse

take opposing positions on major issues, you set a pattern for conflict and failure in future adjustment.

In a time of stress family members expect support from one another. Support starts with the father and mother and filters down to the children. Resentment and dissatisfaction result when one family member fails to respond to the needs of another. Your failure to adjust successfully to the initial tasks after diagnosis largely precludes adjustment by the rest of the family. Trust, honesty, and mutual support are essential in good family functioning. They are impossible to maintain if the family fails in its initial adjustment at the time of diagnosis.

When differences occur, it becomes easier to resolve these differences if the parent whose opinion prevails does not feel as though he or she had "won a victory." Resolving differences should not be thought of as a win-lose game, but as a means necessary for effective adjustment.

Energy Conservation. Children with cancer can have many years of meaningful life ahead. Parents may have many years of stress with the child, but also many years of joy. It is important, then, for parents to conserve their energies for the long haul.

Frequently, parents react to the illness by changing jobs, separating, remarrying, moving, or becoming pregnant. Each additional major change adds stress to an already overloaded circuit, and some of these changes may have negative consequences.

> Nine months after Laura was diagnosed, Mrs. W., who was divorced at the time of the diagnosis, remarried. Initially, Mr. W. was supportive, but as the disease progressed, he began drinking, dating, and leaving the home for long periods. Mrs. W. found that she could not handle both the stress of her daughter's illness and the added burden of her unhappy marriage. As a result, Mr. and Mrs. W. separated.

Sometimes a family doctor or friend will suggest to a couple that they have another child "to take your mind off of things," or "to give you something else to live for." Occasionally a couple will want a child in order to "replace" the child who is sick. Having a child for itself is one issue, but any attempt to "replace" a sick child will result in serious negative consequences, both for the child and for the parents.

In brief, it is wise to evaluate any suggested change thoroughly to

see if it will add unnecessary stress to an already highly stressed situation.

Grandparents–Relatives. Grandparents frequently practice denial as a way of reducing their own emotional pain. They are hurt and feel very threatened by the serious nature of the illness. Parents, then, find themselves in a position where they must not only come to terms with their own grief, but must also serve as a source of emotional support for sorrowing grandparents.

Relatives who are some distance removed from the activity surrounding the illness frequently offer challenges to the reality of the diagnosis. They want to know if the doctor is certain of the prognosis. They may suggest that parents go elsewhere for better treatment or that they seek faith healers. Parents who are desperately trying to cope with their own emotions must often deal with the well-intentioned suggestions of relatives.

Normality in the Home. Probably the most essential and demanding task facing parents is maintaining a normal home life. A child with cancer continues to achieve, develop, and grow. To overcompensate for the illness by showering the child with gifts or by abandoning all previous forms of discipline only confuses the child and may be resented by brothers and sisters. This produces conflict. An example of overprotectiveness and its consequences is the case of Raul, age six.

> Raul lived with his parents and two brothers, ages four and two. Mrs. S. believed her sick child needed ***all*** her attention. She showered him with gifts, kept him home from school, took him on special outings without her husband or other sons. Whenever he was hospitalized, the mother spent the entire time with him and would not let her husband relieve her. Raul became manipulative and demanding. In the hospital he fought all medical procedures and at home he demanded and got everything he wanted. His two brothers, not understanding the situation and resenting the special attention Raul received, became disciplinary problems in their own way. Mr. S. disliked coming home. He could not communicate with his wife, and his three sons were out of control. This family, because of well-intentioned but mistaken notions, allowed the disease to split them apart.

Marriage Strain. Caring for a sick child can strain a marriage. Even when both partners take a unified approach to coping tasks and even

when both are trying to maintain as normal a home life as possible, there can still be periodic strain. Why?

Each partner in a marriage is an individual with an individual emotional mode of expression. For example, one spouse might find great relief in crying and the other may not cry at all.

> Mr. and Mrs. U. had different modes of expression. Mr. U. cried himself to sleep for many nights after the initial diagnosis. Mrs. U. could not cry; instead, she found herself constantly eating more than normal. Mr. U. accused his wife of being hard and cold for not crying. It took time and honest communication for them to realize that both were hurting deeply, but it was not necessary for both to grieve the same way. With this understanding, they were able to support each other and understand and accept each other's mode of expression.

It is not unusual during the illness for a parent to desire increased sexual intimacy with his or her spouse. When this is mutual, it is a source of closeness, warmth, and support. When it is not, it creates conflict. "How can you think of something like that at a time like this?"

Conflict between parents, whatever the reason, will be sensed by the children. It is important not to allow these conflicts to interfere with the normal functioning of the home. Resolution of the conflicts is important to effective family adjustment.

Pre-Illness Problems. In instances where a child with cancer comes from a family already strained by serious problems, marital, financial, legal, or medical, the child's diagnosis comes as just one more blow to an already overburdened family. Many families find it desirable and helpful to seek professional counseling or help. This does not reflect on the family's usual ability to cope, but merely indicates that the stresses at the present time are too much for the family to bear by itself.

Sources of Support. As parents prepare to meet the new demands imposed upon them by their child's illness, it is wise for them to take an inventory of what individuals or systems of belief they can rely on as a source of support in this time of stress. It might be good to look back and analyze who or what helped during previous stressful times.

A group of parents whose children had cancer were asked to list the sources of support they depended upon during the long haul of

their child's illness. Not all indicated the same sources, but the list included: spouse, friends, relatives, hospital staff, religious beliefs, clergy, professional counselors, the sick child himself, and other parents of sick children.

The spouse was a supportive factor in many but not all of the marriages. Some people turned to friends because they accepted the fact that they could not communicate with their partner. The hospital staff was of assistance to many families. Parents as a whole had great respect for the medical competence of their physician and appreciated the doctor's and nurses' understanding and sensitive care of their child.

Religion was a powerful factor in the lives of many parents who had a strong religious belief prior to the diagnosis. Some of their comments were: "My religion and faith in God helped me the most." "I believe in God and derive strength in this belief." "I try to see this all as a part of God's plan." "Perhaps this is God's way of protecting my daughter from future harm."

The strongest source of support seems to have been the presence of an understanding spouse or close friend to whom the person could turn as problems arose.

It is not unusual for parents to derive strength from their own sick child.

> Mrs. L. said, "I kept myself going when I saw how well Shannon handled herself in stressful situations."
>
> Mrs. V. said, "Carole's own resiliency, her enjoyment of life and her total personality kept me going."

Finally, parents find other parents a source of support. Parents of children with cancer are a definite minority group. There are few people in the community who understand how a parent feels. Another mother and father with a child with cancer will understand. This understanding cuts across social, economic, and racial barriers because both share a common problem.

In many hospitals, parents have gotten to know each other while their children were hospitalized or in the clinic. Some of them have organized parent groups that meet at the hospital on a weekly or monthly basis. These parental contacts have served a healthy function in helping parents attain a feeling of mastery and coping over some of the more difficult aspects of the illness and diagnosis.

Goals. In this section we have talked about the demands placed on families whose children have cancer. Not all of these problems are faced by every family. However, knowledge of potential stress areas can be very helpful in the eventual mastery of that stress.

Medical goals are clearly defined by your physician and involve the best possible care for your child. But what about psychological goals? What is your goal for your child and the quality of his life? What about your goals for your other children? Will the suffering of a brother or sister frighten your other children? What about yourself? Will you let this illness fragment you? What are your goals for your marriage? Will the illness be a cause of deeper love, respect, and trust?

PART II: YOU AND YOUR CHILDREN

Most parents express concern at one time or another about what their sick child and well children know about the illness and its consequences. This is not an easy subject for parents to face. We will share current findings with you that may help you to understand and answer your children's questions.

THE HEALTHY CHILD AND DEATH

Concepts of death are age-related in children and differ with intellectual ability and development. We will divide our discussion into four parts, one for each age group: the infant and toddler period (under 3), pre-school period (3-5 years), the early school years (6-10 years), and the pre-adolescent and adolescent period (after about 11). Attitudes and concepts do not change abruptly at the given age, but evolve gradually and with wide individual variation.

Infancy and Toddler Period. During the first two years of life there is no understanding of death, but fear of separation from protecting, comforting persons is present in its most terrifying intensity. While death is not yet a fact for the child going on three, anxiety about separation remains all-pervasive.

Pre-School Years. Sometime between the ages of three and five, most children first comprehend the fact of death as something that happens to others. At this time, the concept of death is still vague. It is associated with sleep and the absence of light or movement, and is not yet thought of as permanent. In contrast to toddlers, most child-

ren of this age are able to withstand and understand short separation. They often respond more spontaneously and with less anxiety to questions about death than do older children. They are also curious about dead animals and flowers. It is especially at this age that children are involved with magic. To wish and to want strongly carry with them the risk that the thought will be carried out. The child often wishes that mom, dad, brother or sister would go away and never return. Hence, his anguish and guilt when a parent or sibling dies.

Children between three and five deny death as a final reality. They believe death is accidental and they themselves will not die.

Early School Years. Attitudes and concepts of children do not change abruptly at any given age, but evolve gradually and with wide individual variation. From approximately the age of six onward, the child seems gradually to be accommodating himself to the proposition that death is final, inevitable, universal, and personal. Many six- and seven-year-olds suspect that their parents will die someday and that they, too, may die, but only in the very distant future.

Children between five and nine show a strong tendency to interpret death as a person. For example, the "death man" carries off those who die. Many children are horrified, confused, and angered at their first discovery of death. In brief, the child under ten is beginning to come to grips with the concept of death, but has not yet attained a well-developed understanding of death.

Pre-Adolescent and Adolescent Period. Piaget, a famous philosopher and writer on child development, suggests that as a child approaches adolescence, at about age eleven or twelve, he is equipped with the intellectual tools necessary to understand both life and death in a logical manner. At about the age of ten or eleven, the fact of the universality of death and the permanence of death finally become understandable.

The child of ten or eleven accepts death as a natural phenomenon and accepts the fact that all men must die and that he himself must die, but his own death is still something that will probably not occur for a very long time.

In summary, the child under five lacks almost all of the mental operations required to form the concept of death, even in a beginning manner, except for his understanding of the concept of separation. By the age of eleven or twelve, the concept of death is fairly well es-

tablished. In the middle years, ages six to about ten, the child has some appreciation of the fact of death, but has not yet come to full adult awareness of the concept.

THE SERIOUSLY ILL CHILD AND DEATH

How does all this apply to the child who has been diagnosed with a potentially life-threatening illness?

Studies of children under five show that fear of separation, fear of abandonment, and fear of loneliness are most important to the seriously ill child.

From the ages of six to ten and perhaps as young as five, children have fears relating to physical injury and bodily harm. Recent studies of six- to ten-year-old leukemic children reveal that, despite efforts by parents and medical personnel to keep the child from becoming aware of the prognosis, he somehow picks up a sense that his illness is very serious and very threatening. He is aware that his is no ordinary illness. The fear of abandonment is replaced in part by a fear of bodily harm and injury and possibly by awareness of his own death, or, at the very least, that something very serious is happening to him.

Children over ten do show a fear of death. In the pre-adolescent and adolescent, this fear takes precedence over other fears. Despite great effort on the part of physicians and parents to hide the diagnosis from them, they can and do become aware of the seriousness of their illness. This awareness, coupled with a lack of communication by meaningful adults, can cause the children to worry. Children in this age group become especially worried when confronted by a conspiracy of silence and find great relief when given an opportunity to discuss their concerns with a sympathetic adult.

Children over ten tend not to ask direct questions of the staff or their parents but instead wait for adults to show readiness to anticipate and deal with their concerns. Therefore, reliance on overt expression of death anxiety may give an incomplete and distorted picture of the actual concerns of the seriously ill child. While some five-year-olds, for example, may talk freely about death, most young children find it difficult to express their feelings openly, and are thus often thought to lack fear and anxiety about the subject. Many of their feelings may be underground, and reports that a particular child has absolutely no fear or anxiety may really only be a report of that child's lack of expression of those anxieties.

Another common occurrence is for older and some younger children with cancer not to let their parents know how much they really do understand about the illness, in order to protect their parents by not having to talk about it. Perhaps the loneliest of all are those children who are aware of their diagnosis but recognize that their parents do not wish them to know. As a result there is little or no meaningful communication; there is no one with whom the child can openly express his feelings of sadness, fear, or anxiety.

> Mr. and Mrs. G. were confident that they had succeeded in keeping all knowledge of her illness from their daughter Lucy, age six. A psychologist showed Lucy a picture and asked her to tell him a story about what was happening in the picture. The child said, "The little girl in the picture is very sick in the hospital. The girl's mommy and daddy are talking to the doctor at the door. The doctor is telling the mommy and daddy that the little girl is very, very sick, but the girl is pretending to be asleep because she doesn't want her mommy to know that she knows how sick she is because then her mommy will cry."

The question is not whether to talk about the diagnosis, since the child usually senses it anyway, but rather how to let the child know that his concerns are shared and understood and that there is willingness to talk about his concerns with him. Moreover, it is important to remember that the worries of the child regarding the possible outcome of his illness are not necessarily the same concerns held by his parents.

Children build defenses to protect themselves from too much pain, but they also want to be told the truth. It is a challenging task for those close to the sick child to recognize the child's defenses and at the same time to be honest and open to questions the child may ask about death or his illness. Meeting this challenge with intelligence, understanding, and compassion may save the child great anguish and strengthen his will to live.

In summary, we can say that the anxiety of the seriously ill child under five takes the form of fear of abandonment, separation, and loneliness. The child between six and ten picks up a sense that his is no ordinary illness; it is very serious and very threatening. He is fearful of bodily intrusion and harm. The pre-adolescent and adolescent is usually very aware of the possible life-threatening nature of his illness and can be most anxious about his possible impending death.

The children come to this awareness despite efforts on the part of adults to keep knowledge of their prognosis from them.

HOSPITALIZATION

Immediately upon admission to the hospital, the child enters a new world. He sees strange machines, he becomes aware of other patients and their conditions. He strives to achieve some kind of order out of the confusion that surrounds him. He quickly senses who on the medical team will answer his questions and he is quick to figure out if mom and dad will give him a straight answer. From the beginning, it is important to give the child the assurance that he can ask any and all questions, express all concerns, and seek answers to what he does not understand in his hospital environment. Constant and meaningful communication on all subjects will free much of the child's emotional energy from the struggle with these many unknowns and direct it more productively toward adjustment to day-to-day problems.

The Younger Child. Hospitalization can be a traumatic experience for any infant, toddler and pre-schooler, especially if the child is removed from the mother upon whom he depends for emotional and social support. Much of this trauma is minimized if the mother remains with the child. Qualified and understanding nurses do not substitute for the mother with the young child. It is not unusual for young children to regress in their development while hospitalized.

The Older Child. Childhood is a process towards independence. Hospitalization threatens that growing sense of independence. The child is taken to the doctor, taken to the hospital, given treatment. He becomes a passive recipient rather than an active doer. The child who is old enough to understand some of the implications of his illness and is told nothing can become rebellious. The child who has been given an explanation at his level of understanding is aware that continuous hospital and clinic visits are necessary to maintain health. He is frequently very cooperative in spite of the obvious infringement on his independence.

The Adolescent. The lack of independence resulting from hospitalization and the treatment of the illness is particularly displeasing to the adolescent. Newly emancipated, he frequently and loudly protests his forced dependence. In the book *Eric* by Lund (Lippincott,

1974), Eric, 17, refused to allow his mother to accompany him to the clinic or participate in discussions with the doctor. As difficult as this was for her, Mrs. Lund respected Eric's need to exert as much control as possible over the management of the illness. Johnny (in Johnny, by O. Sanderlin. Pyramid, 1969) maintained his sense of independence by devoting his energies to excelling in sports. He managed to win a national tennis championship.

Immobility and Negative Feelings. Hospitalization almost always involves some restriction of movement on the child's part. Experiencing difficult medical procedures and continually meeting new people who do all sorts of things to him can build up many negative feelings, especially when the child is given little or no explanation for the procedures and is kept from expressing himself in active, physical play. Tension builds. The child becomes unruly, nervous, and anxious. For the hospitalized child, some form of outlet in play is essential.

The Playroom. Most large hospitals and many smaller ones have playroom facilities as an important part of their medical program. Playrooms have been established to facilitate natural and spontaneous play. When children become involved in play, they relax and become less fearful. They are also better able to cope with their fears involving hospital equipment, medical procedures, and medical personnel. A child who has first relaxed in a play setting and has had a chance to ask questions or to act out his concerns through play is generally a more cooperative patient. Hospitalization can be confusing to a child, but play maintains aspects of normality.

In some hospitals well brothers and sisters can join in play activities, usually in the out-patient clinic. Familiarity with medical equipment and personnel helps relieve their anxiety regarding the welfare of their sick brother or sister.

Playroom personnel are trained professionals with backgrounds in psychology, special education, early childhood education, social work, nursing or recreational therapy. They are part of the team involved in the care of the sick child. In their daily contact with the hospitalized child, they are in a position to observe resistance to medical procedures on the part of one child, excessive fear in another, passivity in another. In other words, they are in a position to observe what a particular child is saying about himself.

Kerry, age 6, drew pictures of four adults all looking like monsters. He explained that one was doctor, the other was nurse, the other was mom, and the last one was dad. He said he was very mad at mom and dad for letting doctor and nurse do all the horrible things to him.

Paul, age 5, found a favorite toy, the doctor doll. He pounded that doll each time he came into the room, and then, relaxed, continued with his art work or puzzle.

The playroom, then, enables medical personnel to get valuable insights into the emotional workings of the child.

Expressions of Anger. As suggested above, children can become angry with the person who administers treatment and with parents for allowing it. It is not unusual for some to become actively rebellious against treatment. Younger children sometimes openly reject parents, making such statements as, "I don't ever want to see you again." "I hate you." "Why do you let this happen?" These statements usually come after a long period of hospitalization during which the child undergoes many painful medical procedures. Children believe in parent-power. Some of a child's faith in parent-power is shaken when mom and dad are unable to prevent these painful procedures. Some researchers speculate that young children, sensing their dependence on nurses and doctors, are fearful of expressing anger directly at them, so they let it all out on mom and dad.

Diagnostic and therapeutic procedures, whether in the hospital or the clinic, are also painful to parents. Some parents feel better if they can remain with the child during treatment. Others are relieved when they are not expected to be present. It is not unusual for the mother of the family to bear most of the physical and emotional burden of clinic visits with the child. When possible, the father's attendance at clinic would be of benefit. This gives him an insight into what goes on and helps him understand the emotional impact of these frequent visits on the mother. It is worth the investment of time to readjust work schedules so that both parents may share the burden of clinic visits.

Death on the Pediatric Ward. Occasionally, a child is hospitalized when another child on the ward dies. There is then a noticeable change on the ward. There may be a flurry of activity as personnel gather. Frequently, parents are seen crying. The observing child may even

know the parents and the dead child from clinic visits and playroom activities. Adults may strain to keep knowledge of the death from the other children in the ward. But the children are aware that something has happened and are doubly attentive for clues to explain it. The situation is emotionally trying for parents and children. It must be handled as circumstances dictate, but parents should be sensitive to their own child's needs for understanding, reassurance, and reaffirmation of hope.

GOING HOME

Parents and children look forward to the day the child will be well enough to be discharged from the hospital. Yet, some parents fear that an acute medical problem may arise that they will be unable to handle. A frank talk with the doctor will be helpful.

Discipline. Establishing normality in the home is a basic task facing parents. The whole family, the child, brothers and sisters, and parents, can have wonderful years together. It would be a shame to waste them on fights, arguments, and jealousy because of misguided notions of discipline. The pampered child is quick to take advantage of an atmosphere of permissiveness and the other brothers and sisters will quickly resent this.

Children, even young ones, are quick to test limits when they return home from the hospital.

> Lori, age 11, announced to her three brothers that she could do anything she wanted and they could not as much as touch her because if they did she would bleed to death and they would be responsible. Fortunately, Mrs. W. heard the entire conversation and informed her daughter that she was not a privileged member of the household and she had duties and responsibilities just like her brothers. Mrs. W. recalled later that she felt it imperative to establish ground rules because all her life Lori was a grand manipulator and viewed her illness as a golden opportunity to get her own way. That was not the last incident, but Mrs. W. met each one head on.

Manipulation is not unusual.

> When Caroline, age 10, returned home, she told her parents she was afraid to sleep in her own room. Thinking this would be for one night, Mr. C. slept in the girl's room while Caroline slept with her mother. The girl has been home for months and is still sleeping with her mother. Mr. C. is quite upset, but Mrs. C. feels "the poor little thing" needs her.

It is not unusual for some parents or well-intentioned grandparents and relatives to shower a child with presents. How must the child feel? What must this make him think?

> Rick, age 15, recalls, "I knew I was really sick when dad bought me a dirt bike. I had wanted one for several years and dad had been adamant in his refusal. Then, two days after I came home from the hospital, there was the bike. Boy, did that make me feel terrible."

Healthy brothers and sisters are quick to sense that there is something seriously wrong with their brother or sister, whether or not they are told directly by the parents. Knowing something is wrong, they will make certain allowances; it is not unusual for older children to enjoy a family outing geared towards the wishes of the sick child. But it is too much to expect them to tolerate constant overindulgence of the sick child.

Overprotection. When a child is released from the hospital, the physician is very definite about what limits should or should not be set on the child's activity. He establishes the ground rules. Unfortunately, many parents try to out do the doctor and set their own—often far more limiting—ground rules. Activities that might tire the child are ruled out. Activities that might accidentally cause bruising are outlawed. Parents spend a lot of time emphasizing what the child cannot do, and often neglect what he can do. Some parents even discourage school attendance. This is one area that can cause much disagreement between the parents.

School. School is "where it's at" for a child. In our society, school serves a social as well as an educational function. School represents normality and a continuance of life, growth, and development. To deny a child the right to go to school when his physician indicates he is able to is to tell him he is not normal, he is not growing and developing, he has no future.

The school nurse functions as the liaison between the home and the school. Her job entails far more than caring for bloody noses and skinned knees. Today in our schools there are many children with medical problems: cystic fibrosis, heart disease, diabetes, to name but a few. The great majority of these children and adolescents do

very well. A large part of their success is a result of a good working relationship between parents and the school. A parent conference with key school personnel often initiates this good working relationship. Here the parents have the opportunity to explain the implications of the child's illness, establish guidelines for school participation, and answer questions posed by the school. A common understanding of the ground rules from the very beginning avoids confusion and misunderstanding as the school year continues.

At the elementary school, there are typically one or two teachers involved with the child, but at the junior high and senior high school level, where numerous teachers and coaches interact with the child, the nurse serves as the source of information. Teachers are concerned, for example, about the amount of school work a child is capable of doing, and if the physician limits physical activity, the coach needs to know what types of activities are suitable. Adequate knowledge possessed by the appropriate school personnel can make school a positive experience.

Even though it is necessary to inform the school of the serious nature of the child's illness, most children loudly protest special treatment. They do not want to get grades they do not deserve. They do not want special privileges. This only makes them stand out from their peers. It is difficult enough for them to cope with their illness. Specialized attention adds to their burden. Parents need to make it clear to teachers from the beginning that special treatment is neither desired nor appreciated.

Sometimes a child is reluctant to return to school after a few weeks' absence. If the parents have the same feelings, the child will usually sense them, and his reluctance will be heightened. It is usually best to make the decision for his return to school matter-of-factly, and then stick with it. After two or three days back in class, things usually return to normal.

A common problem for some children with cancer is loss of hair due to treatment. Today wigs are made so well that they are difficult to distinguish from real hair. If the child decides to wear a wig, people who do not know the patient usually do not suspect that the hair is a wig. If the child decides not to wear a wig, it is important that the child be made to feel comfortable with his decision. It is important that neither the presence nor the absence of a wig inter-

fere with healthy socialization.

Once rapport is established between the home and the school, it will be easy for parents and school to communicate regarding the progress of the child.

Parents might also wish to check with the school regarding their healthy children. It is not unusual for a brother or sister to be cooperative and supportive at home and then act out in school.

> Rick was a 6'2", 185-pound sophomore who periodically engaged in childish behavior. He was not malicious, and never hurt anyone, but he created such a disturbance that it was impossible to conduct class. During a parent conference following one of these incidents, Rick's parents told the teacher and vice-principal that their daughter, age 17, had leukemia and was recently hospitalized. A review of the records showed that Rick had been sent out of class each time his sister was hospitalized. The parents realized that this was no coincidence. Rick was cooperative at home, especially when his sister was sick, but he let out all his anger and frustration at school.

Nursery and Pre-School. What about sending a child of three or four to a pre-school while in remission? Some families have done this with positive results for the child and for the mother. What are some of the positive results?

First, it gives the child an opportunity to play with other children and participate in many worthwhile and enjoyable learning experiences. It also helps the child develop a sense of independence.

Secondly, it gives the child the assurance that mommy always comes back. This assurance may transfer to the hospital setting and permit the child to tolerate short parental absences.

Thirdly, the child meets other caring adults who function as a mother substitute for two to three hours every day or every other day.

Finally, it gives the mother a few hours alone with a younger or older child, or a few hours to be by herself. The strain of coping with a child with a serious illness is very draining. One young mother admitted that it was these short respites while her little girl was in nursery school that enabled her to regroup her forces and continue with daily life tasks.

Nursery school can have a positive role in the young child's quest to live a full and meaningful life.

BROTHERS AND SISTERS

Brothers and sisters of a child with cancer have needs, too. They are sometimes forgotten because of the immediate and pressing problems of the sick child and the emotional upset of the parents.

Brothers and sisters may be confused and frightened by their parents' sorrow and their own inability to comfort their parents in their grief. At the beginning it is sufficient to tell all family members that the child suffers from a serious illness which will require regular and continuous medical care. The children need to know that the disease is not contagious. They will not become sick from contact with the sick child. They also need to know that they are in no way responsible for the illness of their brother or sister.

It is not uncommon for brothers and sisters to have their own problems: headaches, bedwetting, poor school performance, school phobia, depression, anxiety, and stomach aches. They sometimes feel responsible for the illness, and fear that they will be next. They can resent the extra time parents spend with the sick child if they do not know the reason. Some children actually feel angry that their parents allowed this to happen to a brother or sister. Often they are preoccupied with inner fantasies about death. The needs of the well children are real and require wise handling.

Children, even young ones, are sensitive to what is happening. They are aware of a brother's or sister's hospitalization, and of trips to the doctor and to the clinic. They notice dad crying and mother trying to comfort him. They may overhear parts of conversations that are difficult to understand. Children often conspire to figure out what is going on. Pieces of information are gathered, pooled, and analyzed. If the children ask and are put off and shoved away, they will be hurt. This hurt can last a lifetime.

> Lars was seven when his sister died of leukemia. He was never told that she was sick and when she did die, he was sent away to a relative. After the funeral he returned home to find his sister gone and his parents in a state of grief. No explanation was offered and Lars was convinced he had done something that caused his sister's death. He carried this burden of guilt with him until he was fifteen. Academically, he had many problems. His math and reading remained at about the second grade level. His parents were concerned and cooperative, but it was impossible for them to identify the problem. After leukemia was discussed in a health science class, Lars hesitantly told the teacher his story.

Lars wanted to believe that he was not responsible for his sister's death, but he needed to hear it directly from his parents. A conference was set up, and with the support of his teacher, Lars told his parents his feelings of guilt. The parents were astonished. They had no idea their son felt any responsibility. Through many tears, they told him the entire story and tried to reassure him that in no way was he responsible. In fact, he had been a source of comfort and support to both his sister and his parents.

Thanks to recent medical discoveries, a child with cancer can look forward to many years of life. Since that is so, it is essential that steps be taken from the very beginning to insure as normal a home life as possible. One of these steps involves preparing brothers and sisters.

It is often hard to believe that brothers and sisters really love one another, especially when they are fighting and screaming at each other. But when a serious problem arises, they are usually genuinely concerned. This concern shows itself in different ways. In one family, the fifteen-year-old son was greatly concerned about his mother's well-being. "Mom, you look so worried. You have so much to do; you look so tired." His nine-year-old sister, in contrast, had fantasies about the "scary" medical treatment her five-year-old baby sister was receiving at the hospital. She became physically ill every time her little sister went to the clinic. The mother one day took the nine-year-old with her to the clinic to show her just what did take place. The reality of the clinic visit went a long way in allaying the fears and fantasies of the concerned older sister.

Children faced with a serious illness in the family need all the support a parent can give. This support must be continuous and must extend for years. As children grow and develop, their understanding of the illness changes, and with it their questions. It is a delicate task for parents to recognize these changes and answer questions, both for the sick child and for his healthy brothers and sisters, at the child's level of understanding.

Young children believe in parent-power. The parent who listens, who answers questions simply but adequately, who leaves openings for the child to voice any concern, is building a bridge of love and communication that will endure. This pattern of honesty and openness can ease the pain of the illness of a child with cancer by strengthening the bonds of love and communication between all members of the family.